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Clinician views of patient decisional conflict when deciding between dialysis and conservative management

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Clinician views of patient decisional conflict when deciding between dialysis or conservative management: qualitative findings from the PAlliative Care in chronic Kidney diSease' (PACKS) study.

Short title: Clinician views of patient decisional conflict when deciding between dialysis or conservative management.

Key words: Decision making, decisional conflict, palliative care, nephrology.

Abstract

Background Only a paucity of studies have addressed clinician perspectives on patient decisional conflict, in making complex decisions between dialysis and conservative management (renal supportive and palliative care).

Aim To explore clinician views on decisional conflict in patients with end-stage kidney disease

Design Interpretive, qualitative study

Setting and Participants As part of the wider National Institute for Health Research, PAlliative Care in chronic Kidney diSease' (PACKS) study, semi-structured interviews were conducted with clinicians (nephrologists n=12; 7 female and clinical nurse specialists n=15; 15 female) across 10 renal centres in the UK. Interviews took place between April 2015 and October 2016 and a thematic analysis of the interview data was undertaken.

Results Three major themes with associated subthemes were identified. The first, "Frequent changing of mind regarding treatment options," revealed how patients frequently altered their treatment decisions, some refusing to make a decision until deterioration occurred. The second theme, "Obligatory beneficence" included clinicians helping patients to make informed decisions where outcomes were uncertain. In weighing up risks and benefits, and the impact on patients, clinicians sometimes withheld information they thought might cause concern. Finally, 'Intricacy of the decision' uncovered clinicians' views on the momentous and brave decision to be made. They also acknowledged the risks associated with this complex decision in giving prognostic information which might be inaccurate.

Limitations Relies on interpretative description which uncovers constructed truths and does not include interviews with patients.

Conclusions Findings identify decisional conflict in patient decision-making and a tension between the prerequisite for shared decision-making and current clinical practice. Clinicians

also face conflict when discussing treatment options due to uncertainty in equipoise between treatments and how much information should be shared. The findings are likely to resonate across countries outside the UK.

(287 words)

What is already known about the topic? People diagnosed with end-stage kidney disease (ESKD) face a difficult decision-making process and choices regarding renal replacement therapy are perplexing, multifaceted and preparation for treatment often suboptimal. Frail patients with multiple co-morbid conditions may find it challenging to determine the benefits of renal replacement therapy and how it might fit into their existing lifestyle. Some may opt for Conservative Management (CM), a palliative care approach aimed at improving quality of life until death, without dialysis. Clinicians' views on decisional conflict in patients deciding between dialysis and CM are largely unknown.

What this paper adds? Patients are unlikely to fully appreciate the severity of their condition if clinicians act to prevent discussion of declining health and approach of death. This study uncovers a conflicted decision-making process along with confusion surrounding the benefits, risks and side-effects of treatments in end-stage kidney disease. Patients frequently change their mind over treatment options. Clinicians counsel patients to assist them make the decision that clinicians think would be in their best interests. There continues to be a reluctance to focus on the negative aspects of treatment, such as difficult symptoms and limited prognosis.

Implications for practice, theory or policy?

There is a distinct lack of knowledge about how practitioners assist patients in their decision-making, particularly those for whom dialysis may proffer little benefit. There is an ongoing need to provide education and training on this topic. Decision aids which encourage people to be more actively involved in decision-making and improve risk perceptions and congruence between the choice made and patient values might be a helpful addition to renal clinical practice.

Background

Renal replacement therapy (RRT) has steadily increased due to population ageing and epidemiological factors such as the growing prevalence of diabetes and concomitant vascular deficits¹. Global incidence rates for RRT range from 12 to 455 (median 130) per million population². The international population who opt not to dialyse has not been assessed³ although this recourse is recognised as a treatment option in many countries⁴. People diagnosed with end-stage kidney disease (ESKD) face a particularly difficult decision-making process^{5 6}. Choices regarding renal replacement therapy are perplexing and multifaceted⁷. Frailer patients with additional co-morbid conditions may not envisage any clear benefits of renal replacement therapy^{8,9}. Impaired cognition may have further negative impact on decision-making processes¹⁰. Some patients may opt for Conservative Management (CM) aimed at improving quality of life until death, without dialysis, supported by an interdisciplinary team¹¹. To reach an optimum treatment decision with a patient deciding between dialysis and CM, a shared decision-making approach involving members of the healthcare team is advocated^{12,13,14,15,16}. “Patient-centred care” focuses on patients and their carers rather than their diseases¹¹ and is synonymous with care responsive to the needs and values of patients^{17,18,19}. Sharing of information should include treatment options, risks and benefits of treatments and an informed exploration of preferences and values^{8,16,20, 21}. Renal clinicians tend to focus on biomedical factors and have an inherent instinct to prolong life²². Nephrologists often struggle to explain the complexity of illness, tending to avoid discussions of the future^{23 24} in order to maintain hope²⁵. Morton and colleague’s systematic review²⁶ on decision-making regarding treatment for chronic kidney disease reported a lack of choice in the medical decision, a deficiency of information and resource constraints, with needs of patients and families not being met. Poor timing of information about all possible

treatment options may result in haemodialysis being the most frequent choice for patients with end-stage kidney disease²². Decisional conflict is a measure of uncertainty concerned with treatment choices and patients' confidence in making decisions²⁷. It is likely to arise when there is outcome uncertainty⁵ and may impact on the quality of the decision²⁸. Decisional regret is a term describing a sense of self-blame for a decision which failed to produce a desired outcome²⁹. Decisional conflict usually accompanies decisional regret and may contribute to patients apportioning blame to clinicians for a poor decision²⁸. Clinicians have a fundamental role to play in helping patients make patient-centred decisions and may be assisted by decision-aids which have been shown to improve decision-making^{27, 30}. If patients make informed decisions, decisional conflict is likely to be reduced. The difficulties inherent in the decision-making process related to choices between dialysis or CM, arise from the limited evidence on which types of patients might fare best³¹ and limited guidance on best practice^{21, 32}. The National Institute for Health Services 'PAlliative Care in chronic Kidney disease' (PACKS) study³³, is exploring quality of life, frailty, performance, cognition and decisional conflict in patients who decide not to embark on dialysis³⁴. It is also investigating the economic costs of providing palliative care services, and the impact on carers, and is open across 10 renal centres in the UK. It will complete in May 2017. This paper reports the qualitative component of the PACKS study which aimed to explore decisional conflict in patients from the clinicians' perspective and the use of decision aids in clinical practice.

Methods

Design and Setting

Interpretive description, a qualitative methodology, was employed to inform understanding of decisional conflict in patients with kidney disease making treatment decisions from the

perspective of clinicians^{35 36}. Semi-structured interviews were completed with nephrologists and clinical nurse specialists recruited from 10 of the 70 main renal units in the UK (five in Northern Ireland, four in England and one in Scotland). Each unit offers patients renal replacement therapy or CM. We used interpretative description of interviews with clinicians, to generate knowledge related to the clinical context. The ontological and epistemological traditions of human science research, guide interpretive description ³⁷, blending hermeneutic practices and the empirical methods of qualitative methodology. This methodology rejects the view of a single, absolute reality, assuming existence of multiple realities, related to context, and subjectively constructed through social interaction³⁶. It aims to interpret the world of the participants, exploring lived experiences in everyday situations in practice and is concerned with human experience. Interpretive description acknowledges the co-construction that occurs through shared understandings of the researcher and the participants and identified through constant comparative methods ^{38 39 40}. The findings can produce new theory and inform clinical thinking, inventive care practices, and the development of policy.

Questions for the interview were based on and extracted from the Decisional Conflict Scale (DCS) ⁴¹, a 16-item scale used to assess patient uncertainty about medical decisions. The DCS uses structured questions to elicit responses related to decisional conflict. In the present study the DCS questions were adapted and employed within a semi-structured interview to elicit rich, detailed responses related to decisional conflict, its identification and management. For example, one question on the DCS asks: ‘Did you know the benefits of each option’ and requires a Likert scale response between ‘strongly agree’ and ‘strongly disagree’. This was altered to an open ended question, ‘Do you think patients know the benefits of each option offered to them and why?’ (Table 1). One additional question was asked – ‘What guidelines/decision tools do you use with your patients when helping them make treatment decisions?’

Participants

A purposive sampling technique⁴² was used to identify nephrologists and renal clinical nurse specialists at the units participating in the PACKS study, who met the inclusion criteria, which included being employed in the renal specialty and with experience of managing clinical consultations of patients with stage 5 chronic kidney disease who opt for CM. This permitted a variety of experiences across renal units. Purposive sampling enabled the researcher to choose individuals whose experiences helped achieve the aims of the study and who could provide information-rich experiences⁴³. Potential participants were identified with the ten Principal Investigators at each site, and approached by email or in person, by the Chief Investigator.

Interviews

Once written informed consent was received, participants were interviewed face-to-face in an outpatient office (n=20) or over the telephone (n=7) by the Chief Investigator, an experienced qualitative researcher. Interviews were completed between April 2015 and October 2016. The interviewer presented herself as an unbiased nonclinical observer, with previous experience in nephrology nursing, interested in understanding the views of the participants. She was known to some in her role as Chief Investigator in the PACKS study. Interviews were audio recorded and transcribed verbatim. Transcripts were read and re-read by the interviewer and one other member of the research team (SH). Coding was undertaken and passages of text identified that discussed topics similarly. Coding allowed for comparisons and identification of patterns in the data⁴⁴. All other team members read a selection of transcribed interviews in order to compare insights and developing themes. The transcripts were not returned to participants. Interviews continued until data saturation, and no new codes were identified⁴⁵. Field notes were recorded after interviews and these informed data interpretation.

Data Analysis

A thematic approach to analysis⁴⁴, which followed a process of examining emergent patterns or themes, was applied to the data. It commenced with initial data analysis by the Chief Investigator using Microsoft Word to facilitate coding⁴⁶. Guidance by Hahn⁴⁷ was followed and features of Word were used to organize the analysis of data and as a means of facilitating efficient qualitative coding. Initial coding was undertaken and codes subsequently reduced and summarised based on meaning. Finally data were refined into overarching themes supported with rich quotes from participants. Analysis, discussion and checking of findings occurred with a second member of the research team (SH), and a random selection of interviews were shared with the wider team to share insights and initial findings.

Participant characteristics

37 clinicians were invited to participate in the study. Nine did not respond and one refused due to workload. 27 clinicians participated in interviews and included nephrologists (n=12; 7 female) and clinical nurse specialists (n=15; 15 female). The average years of renal healthcare experience was 18 (range 10-33). Participants ranged in age from 30-39 years (n=6), 40-49 (n=14), 50-59 (n=7). Three participants were Asian, two Afro-Caribbean, two Chinese and 20 white (see Table 2). Interviews lasted between 19 and 35 minutes.

Findings

THEME 1: Frequent changing of mind regarding treatment options

Clinicians described how patients regularly changed their minds about treatment options ‘toing and froing’ as treatment decisions were ruminated. The clinical condition and natural history of each patient’s illness often impacted on this indecision and increased symptom burden usually precluded a change of mind.

So there is so much time for changing of minds and for one week, feeling okay, and then maybe a bit of a urinary infection and feeling so unwell, and then back to normal ...then decisions can change and they'll say I do want it, or

I don't want any treatment, and then they say I do want treatment, and then they come back and say I don't want it, and change their mind again (CNS09).

*CNS=Clinical Nurse Specialist

191
192 Clinicians laughed demonstrating humour, whilst expressing exasperation and occasional
193 sadness at these constant changes. They appreciated difficulties presented to patients when
194 attempting to make an informed decision regarding treatments of which they had no prior
195 experience.

Ha-ha [laughing], I'm trying to think percentage-wise, but we get patients that choose hospital dialysis as their first option, and then it would be peritoneal dialysis, and then it would be conservative treatment, but I have seen some medical clinicians encourage those patients to change their mind, and some have changed their mind, and I have seen patients go on, start dialysis, hate it, and withdraw from dialysis, even though their original plan was never to start this, and I think, well, it is sad (CNS18).

And then, when the time comes, you're saying, "You've made that decision", "No, I think I will have dialysis now," you know [laughing], they will change their mind (CNS08).

196 Three subthemes help elucidate the reason for frequent changes in decision-making.

197 *Denial and fear*

198 All clinicians, bar one, felt the decision whether or not to embark on dialysis was bewildering
199 for patients. They described patients in denial, often fearful of the decision, anxious that they
200 were taking a '*proactive decision towards death*'. Cognitive dysfunction, language barriers
201 and uraemia were reported as contributing towards perplexity. Additionally and conversely,
202 patients often delayed decision-making whilst feeling reasonably well and some avoided
203 meeting with healthcare practitioners in order to avoid a decision.

They might be in denial. Their educational level might not be that good. Also, there could be a language barrier. They could be uremic if we get referrals at a late stage. Their cognitive function might not be as great as we expect. So, for all those reasons, I don't think it is 100% (CNS04).

It's people who are brought back continually to clinic, and keep coming back, because they're well, ...they will not decide until nearer the time if they really do want dialysis, and if in their hearts they don't know they might stop coming – they will cancel their appointments (CNS10).

204 This caused consternation amongst clinicians observing the turmoil of patients confronting
205 deterioration and progress of a disease that would ultimately lead to their death. Clinicians
206 aspired to encouraging patients to accept their diagnosis and treatments but attempted to

207 soften the impact of diagnosis and reduce fear; taking an optimistic stance and offering
208 encouragement throughout the patient denial process.

So they focus more on the bad side and what will happen to them because they think that once they have kidney failure, they die. There is no hope. So it depends on the staff, how you educate them, how you kind of give them the information that will give them inspiration. Look, you're not the only one But it's so hard because they're already in denial and you're trying to give them a positive side. You can have this option. It's the same as supportive care. You're not telling them that you're dying. You also tell them about other patients. "We have this patient, but they are doing well," so you kind of in a way encourage them as well, don't tell them all the side effects, and you tell them "You are fit person – it could be good to you - you don't scare them (CNS05)

209

210 *Influences from families and other patients*

211 Families and other patients impacted upon and helped inform the decision-making process.
212 Families who displayed difficulties accepting a loved one's diagnosis of kidney disease might
213 encourage patients to accept a treatment they had previously declined. Patients, reluctant to
214 cause family upset, might be persuaded to change their decision in such a setting, especially
215 if they were experiencing difficulty with acceptance of clinical status themselves.

I think a lot of elderly people are forced into dialysis when they would otherwise not have preferred to have dialysis. Their families are keen for them to live longer and so they're pressured into getting dialysis (N13).

I think the bigger problem is that patients' relatives, who, no matter what you tell them about dialysis, feel that their mother or father should be on treatment, and I think that's a much more difficult thing for the patient to ignore because they're with their family member, you know, most of the time, and if it's causing the family member upset, they're probably just going to go ahead with the dialysis. So that is a big issue that we have (N16).

Sometimes they start to hear things or see things from other patients, if they're around the hospital and talk to other people (CNS06).

216 When patients deteriorated and couldn't participate in the decision making process, some
217 family members took responsibility, assuming that a lack of capacity had supervened; this
218 occasionally resulted in them overturning the patients' previously indicated preference.

Unfortunately, he was beginning to get uremic and beginning to lose capacity and it all completely unraveled. I feel at that point that the family had made a decision for that patient, that the patient hadn't necessarily made themselves but the patient had lost capacity at this stage to make his own decision (N09)

219 Some family members demanded they be heard and listened to, opting to take responsibility
220 for the decision. In some instances the patient appeared unable to voice an opinion.

Some families just demand "I want my dad to dialyse," they don't give their relative a chance to decide...It's very hard because the family can be very, very strong.... "No, I decide, you know - I am the head of the family and I decide (CNS04)."

The family, usually Asians, they're very strong and say "No, we want our mum to dialyse." So, even if we decided in the clinic already that they won't dialyse, they will say to another doctor that "Oh no, we want our mum to dialyse," and that doctor often says "Yeah, we will dialyse your mum (N06)."

221

222 *Clinician encouragement to change mind*

223 Although patients frequently changed their treatment decisions, clinicians reported
224 encouraging this phenomenon, recognizing and appreciating the complexity inherent in such
225 decisions. They felt it was almost impossible for patients to make an informed decision about
226 treatments which they hadn't personally experienced.

I'm quite content and comfortable if they want to change their mind either to go towards dialysis or to come away from dialysis, and I would deal with them as and when. I don't think anybody chops and changes every five minutes, but it's a big decision and I think people have got to have the right to be able to change their mind (N15).

It's really only when you're in it that you're truly informed [laughing], no matter how much education you've had about something (N13).

227 Although they realised that fluctuating between decisions meant some patients wouldn't be
228 prepared appropriately for treatment, clinicians accepted that patients needed to be allowed to
229 change their minds right up until treatment commenced. That said, if the decision could be
230 finalised in good time, clinicians felt patients would be more prepared for treatment:

231

You really hope in your heart though that they don't change their mind because, obviously, you know, getting a line in, last minute, unplanned, isn't good but you do tell them they can change their mind (CNS21).

232 **THEME 2: Obligatory beneficence**

233 *In the patient's best interests*

234 Although clinicians felt they had to help patients make the best choices, they didn't wish to
235 cause harm. Their role was to advise patients on treatment options, weighing up what
236 information required sharing to inform patient decisions. Some clinicians believed that they
237 had a good knowledge of their patients' values having, in some cases, treated them for many
238 years. They felt able to act in an advocacy role on behalf of the patient although some
239 clinicians were less comfortable with this approach. Views varied on what constituted open
240 and informed patient- centred decision making. It was thought that enabling a patient's
241 autonomous decision could potentially conflict with the beneficent or non-maleficent role of
242 clinicians to ensure what was in the patient's best interests.

We say it's always about patient choice, but there's no doubt that there's a large medical steer in that. You know, if you show someone all the options, a lot of the time, they say, you know, "What do you think?" and obviously, you can guide people down a path because you think it's the right thing for them (N11).

I feel our patients are aware of some treatment options, but maybe not all treatment options. There is a slight bias with the doctors probably in giving treatment options out because we sometimes make assumptions that some treatment options may not be suitable (N16)

So I think, as a Renal Team, we do have to be very careful that we don't go in with our fixed ideas, and we do have to listen to the individual because they are an individual, and that has challenged us (CNS20).

243 In order to help patients with their decision it was felt an individualised, bespoke approach to
244 care was indicated. This precluded the use of decision aids or guidelines, which were
245 generally viewed negatively and unhelpful within such a multifaceted and multifarious
246 decision-making process. Laughter and humour were again apparent within such narratives.
247

Not really, no. We don't have decision tools. We just give the information to them and then ask them to make the decision (CNS01)

There is one we use...I've forgotten the name of it. I use it on the computer. I've completely forgotten the name. I haven't used it in a while (CNS03).

Consultant: With treatment decisions [Decision Aids]? No.

Interviewer: That's alright. Why are you laughing?

Consultant: Because we've talked about it, you've got all these various sites, mainly generated from England, – UK Kidney Care, the English sites, and I think when you have a frail patient, who's got multiple comorbidities, it's quite difficult to get them to go through all of that [laughing]... (N14)

248 Some clinicians felt that their clinical judgment was sufficient and that it was relatively easy
249 to identify the most suitable choice of treatment.

No. I just usually use my own clinical knowledge, depending on their comorbidities. Sometimes it's clearly obvious what's best for them and you don't need a decision aid by any stretch of the imagination [laughing]. Sometimes, the nurses will be part of the decision aid ...But no, we don't have any formal policies, as it were. The only time I could quote any sort of numbers or anything at them is in supportive care if they're asking me about life expectancy. Then I might talk to them a bit about certain evidence that they'll do less well on dialysis than supportive care, but we don't have any formal algorithms, no. It's all sort of on an individual basis really (N06)

250

251 *Influencing the decision*

252 Some clinicians acted to induce a patient to make a particular decision if they felt they were
253 not choosing an appropriate treatment. This was again undertaken within an advocacy role,
254 with the best interests of the patient paramount.

I have had patients who have refused to engage in dialysis planning, and they're clearly not wanting conservative management. And I have been very naughty and said "Look, if we don't move forward with this dialysis planning, the alternative is you don't get dialysis and I'm sending you to somebody to talk about what it means not to have dialysis," and I've done that, and then they come back and they say, "Right, okay, I'll have dialysis now... You may say that's very naughty, but it's helpful for the patient (CNS10).

We keep telling them you need to be realistic, you're still well, you're working, you're very active, so, I think the best thing would be to embark on active treatment, but, some patients will just say... "No, I don't really want it. But we keep on, telling them that you really need it at the moment "No, we really need to be realistic – you need to make a realistic decision regarding your care." A patient recently said, "I'm doing this for you," and I said, "No, it's not for me, it's for your own good (CNS01).

I mean, we don't coerce them into it, but we do guide ...because you know yourself which is the best modality for a patient, so we would guide, but... they have the support of their families as well. So there's a lot of guidance from all directions (N14)

255

256 When asked how informed patients were about the risks and side-effects of treatment, some
257 clinicians described deliberate withholding of unpleasant information. Sometimes it was felt
258 that too much detail about dialysis side effects could lead to a refusal to accept dialysis. This
259 was particularly applicable to older, frailer patients' although some clinicians were unhappy
260 with this approach. Clinicians justified withholding information believing that patients might
261 not want prognostic detail. They felt that providing a negative viewpoint might coerce
262 patients to think about concerns they had never considered.

You know, an elderly, frail patient, you're not going to overload them with a lot of scary complications and side-effects because you might potentially upset them... So, again, there's a wee bit of bias in patient selection as to how much negative information you want to give a patient (N16).

I think we could do better in trying to make people realise that a major organ within their body is failing, and that they have to face that reality. So, I don't think we really [sighing]... We could do better addressing end of life issues and looking at the impact of prognosis on all of that. I suppose we find that hard within Renal because it's so difficult (CNS20)

I don't tell them explicitly about life expectancy ... The reason I don't do that is because I think at that stage in life, patients still don't feel that renal disease, nor do I think they ever will think that renal disease is like a terminal illness, and I think it's wrong to introduce that concept "Oh, by the way, do you know you've got the life expectancy of a patient with lung cancer?" and you're 80 and about to go onto haemodialysis (N09).

If they haven't asked me, I may be telling them something they don't want to know, and even by asking them, "Do you know what your life expectancy is?" that's suddenly putting an idea into their head which wasn't there (CNS23).

263 **THEME 3: The intricacy of the decision**

264 **A momentous decision**

265 Clinicians articulated the enormous significance of the treatment decision defining it as '*the*
266 *most complex in medicine*'. Many hours were required to assist patients in their decision-

267 making and if treatment was commenced it was subsequently difficult to withdraw.
268 Clinicians generally agreed that substantial time and thought should be devoted to the process
269 to ensure appropriate interventions. The cost of treatment was also alluded to in light of poor
270 prognosis and reduced quality of life.

This is one of the most complex areas in medicine to make decisions on, and it's becoming more complex because of the types of patients we're now being asked to deal with... These are patients that are elderly and frail, with lots of comorbidities, sometimes very severe, like dementia, cancer, and these are the decisions which are becoming really, really difficult to make, and no consultant I know can make these decisions easily. If they do make them easily, they're doing it wrong. These decisions are extremely difficult. They have to be individualised for each patient. They take hours of talking. Very rarely is this decision easy in the majority of elderly frail patients (CNS02).

Once you initiate treatment, it becomes really difficult to stop it again, so we do not want to initiate treatment inappropriately in patients where we're not going to benefit quality of life or their lifespan because they're going to die from heart failure, dementia, cancer, whatever. It's one of the more difficult areas in medicine to explore. It's also an extremely expensive therapy that we don't want to use inappropriately in a very cash-strapped NHS, and so we have to make sure that we're doing the right thing for the patient and use this treatment as appropriately as we can, otherwise, if we just willy-nilly start people on dialysis, without any thought whatsoever, that would be a disaster, for patients, family, but also for the NHS in general (N06).

No, I don't think the decision is easy for them to make, and it doesn't matter what age the patient is. Everybody, at different stages of life, has their own personal lives, their own issues. Dialysis or no dialysis, and thinking about the end of life is huge and I don't think, you know, that... we can really appreciate the impact of trying to make that decision, because we can give them as much information as we like, but you can't come up with every scenario that this patient's going to go through, and you can just give them a picture, a snippet (N18).

271

272 *A brave and informed decision*

273 Clinicians may have attempted to influence the decision of patients in an attempt to help them
274 make an optimal decision but they applauded patients who made an autonomous decision for
275 CM and talked of a 'brave decision'. These patients had re-evaluated their lives and what
276 they hoped to gain by living longer. This was viewed as a 'crossroads' in life where a patient
277 could accept their failing health and impending death.

To come to that, you would have had to re-evaluate where you are in life and what you hope to gain from living longer, and so, you know, it's that crossroad where you say, right, I'm at the point when my physical and mental health is such that I don't think it's worth living that much longer and I accept what I've got at present and so be it (N13).

If they're given the information in the proper way, they're beginning to face the reality that life is fragile, very fragile, and I think they probably are to be very much admired, for the decisions that they make. It's so unpredictable, renal failure as a whole, so unpredictable ... it's not easy (CNS20).

278

279 The patients who opted not to dialyse and were clear in their decision-making appeared to
280 have less decisional conflict according to clinicians. They rarely altered their decision, even
281 though clinicians reported regularly checking that they were satisfied with their decision, as it
282 was viewed as inevitably leading to death.

"I'm old, I've done this and I've done that, and do you know what, if I die, I die." Do you know? And then you know that they are satisfied and they say, "... I was happy with my life," you know, I have done this and that and I'm happy to go if I have to go" (CNS05).

I think if properly supported, patients who make that decision [conservative management] do in fact stick to their decision. We are very careful to ensure that, even towards the very end, we say to them that they can change their minds. But in my experience, none have (N13).

283

284 **Benefits, risks and prognostic uncertainty**

285 Clinicians reported that patients were generally able to identify the benefits of treatment but
286 focused less on risks and side-effects. They found difficulty helping patients identify these
287 phenomena as their views often differed to patients. Clinicians tended to focus on the more
288 medical and technical aspects of care but were aware that patients often adopted a more
289 personalised perspective.

It's very difficult because healthcare professionals and patients often perceive that the other is talking about something else – Often, we're interested in the conversation about the need to start dialysis based on a combination of symptoms and biochemical results, whereas, what we probably should be discussing [laughing] is what matters most to the patient. But there needs to be very transparent conversation, which often doesn't happen, about time at home, time to death, which is very difficult to put your finger on, and the likelihood of hospitalisation. And it's very difficult and the bottom line is I'm not sure that in all my patients understand what benefits matter most to them when making these decisions about electing to have or not to have dialysis (N12).

290 Clinicians also felt patient experience was individual in nature. Not having experienced the
291 situation patients found themselves in, clinicians often felt unable to appreciate the subtle
292 needs of each patient and their individual understanding of the situation at an empathetic
293 level. Often this led to a more cautious and safe and clinical approach.

So, probably, we're too conservative about our conservative management [laughing] because there's probably a lot more people who shouldn't do dialysis but we kind of think, mm, give them...give them the benefit of the doubt and try it, saying that they can stop if they don't like it, but, you know, once you start something, it's harder to stop than never starting it in the first place (N11)

294 Clinicians discussed the uncertainty of prognostic predictions and the risk of giving
295 misleading information related to prognosis which could prove erroneous. This was made
296 more difficult by the fact that most clinicians could cite an example of a patient who had
297 done well on dialysis against the odds.

He was unconscious, very ill and in his eighties. You'd say this man's too sick to do anything, but we talked to his family and they said, no, they wanted to give him the chance at dialysis, and we did. He lived for at least another three years at home with his family and was eternally grateful – every time I came in, he was "Thank you," oh...and it was like, well, I just don't know. We don't know what's going to happen in any individual patient, so you cannot be too sort of, judgmental on what to do

298
299 The difficulties in predicting outcomes led to conundrums where clinicians focused on
300 positive aspects of treatment largely on the basis of predictive uncertainty regarding
301 treatment.

I think we sometimes tend to focus on the positive points of each option rather than dwelling on the negative aspects of the alternate option (N11).

It's probably something that we don't go into a lot of detail with them because, obviously, we don't really know the risks ourselves of what will happen along the way (CNS21)

302

303 **Discussion**

304 In exploring decisional conflict in patients deciding between dialysis and CM it is clear that
305 clinicians are in an unenviable position of attempting to assist patients in making decisions
306 where clinical outcomes are uncertain. Clinicians face uncertainty when making prognostic

307 predictions, as precise predictions are likely to be misleading and may prove ultimately
308 inaccurate. Patient-centred decision-making is challenging and is hindered by confusion
309 surrounding the balance of benefits versus risks of treatment, with patients frequently
310 changing their minds over treatment options. In the present study, clinicians discussed their
311 reluctance to focus on the negative aspects of treatment, such as difficult symptoms and
312 limited prognosis in the face of uncertainty. Unfortunately, an attempt to avoid discussion of
313 declining health and approach of death is likely to lead to patients being unlikely to fully
314 appreciate the clinical status and severity of their condition; the fact that their health will
315 continue to fail and that death will inevitably follow. In addition, if the difficult aspects of
316 treatment options and symptomatology are not clearly extrapolated for patients, their
317 decision-making may well be skewed towards dialysis rather than CM.

318
319 There is a clear need for an honest and open shared decision-making approach to enable
320 people with ESKD to decide what treatment might suit them best, although it is
321 acknowledged that prognostic uncertainty makes this difficult. In helping patients make
322 decisions, clinicians face conflict themselves as they decide what should be discussed and
323 whether appropriate influence is indicated. In discussing patient decisions, clinicians have
324 uncovered their own conflicts when deliberating treatment options. Recurring, expressed
325 humour, in many interviews, indicated a degree of incongruity or perception of things not
326 being as they should; also perhaps indicative of a conflicted situation for these clinicians
327 living and working with uncertainty.

328 In this study, clinicians faced similar dilemmas to those previously highlighted^{23,24,25,48} often
329 preferring to avoid difficult end of life discussions for fear of reducing hope. Discussion
330 about CM may be constrained by a combination of poor timing of information and reluctance

of clinicians to be more explicit about quality of life and survival with dialysis. That said, it is highly likely that patients and clinicians both differ in their experiences of decision-making. Shared treatment decision-making is a term that remains elusive²¹. Many practitioners believe the concept of shared decision-making is clear and that a definition is not required, leading to varied interpretations by patients and clinicians with resultant ambiguity and misunderstanding^{49 50 51}. Outside of the nephrology discipline, shared decision-making has a stronger evidence base, particularly in cancer, and decision aids are frequently used in these arenas^{27,50}. A recent Cochrane review of decision aids to help people facing treatment or screening decisions²⁷ found high quality evidence that decision aids, compared to usual care, improve knowledge of options, improve communication, encourage active involvement in decision-making and improve risk perceptions and congruence between the choice made and patient values. The Dialysis Decision-aid Booklet, 'Dialysis: making the right choices for you'⁵² should prove to be a useful tool but requires a CM component for deployment within this patient group. The use of decision aids has demonstrated a poor uptake within nephrological circles and there are few studies of interventions in the current literature.

Limitations

This study makes tentative claims of generalisability because although it relies on interpretive description rather a constructed truth³⁸, it is likely that many of the findings will resonate with practitioners globally. It encompassed views garnered from practitioners from across ten renal units in the UK so some similarities in experience may be drawn. The results may be influenced by the first author's personal biases, but a second author (SH) assisted with the data analysis, and interviews were shared and analysed by all authors. The study did not include interviews with patients.

Conclusion

Clinicians report decisional conflict, and uncertainty, in patients making decisions between dialysis and CM, and feel conflicted themselves. They endeavour to act as a clinical advocate acting in the patients best interests, offering guidance based on the treatment they believe

might suit the patients, whilst at times withholding information. A more patient-centred approach to decision-making is required^{27 53} with additional education and training although equipoise is acknowledged . Interventions aimed at increasing comprehension of this disease and its' treatments may reduce decisional conflict and augment decisional quality, but such interventions have been rarely tested within the territory of renal medicine.

(3330)

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HN designed the study and drafted the paper. Data acquisition, HN. Initial data analysis/interpretation, HN & SH; subsequent data analysis/interpretation, all authors; each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved. HN takes responsibility that this study has been reported honestly, accurately, and transparently; that no important aspects of the study have been omitted, and that any discrepancies from the study as planned have been explained. All authors revised and gave approval for a final version of the paper.

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